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AUTHOR Sitlington, Patricia L.; And Others
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ABSTRACT

The parents of 14 Iowa individuals with severe/profound mental disabilities were interviewed 1 and 3 years after their sons/daughters graduated from or "aged out" of high school. Two categories of information were sought concerning the adult adjustment of these individuals: (1) general status variables including marital status, place of residence, agencies contacted about employment opportunities, financial resources, leisure activities, means of transportation, sources of help in resolving problems, and amount of postsecondary training; and (2) employment variables including location of employment, wages, number of hours worked per week, and job benefits received. Results indicated that, both 1 and 3 years after exiting high school, individuals were very dependent upon others for housing, transportation, and financial assistance. Ten of the 14 individuals were employed 3 years after high school, but all in sheltered workshops with very low wages. There was little change in the life circumstances of the individuals between years 1 and 3. (Includes 20 references) (Author/JDD)

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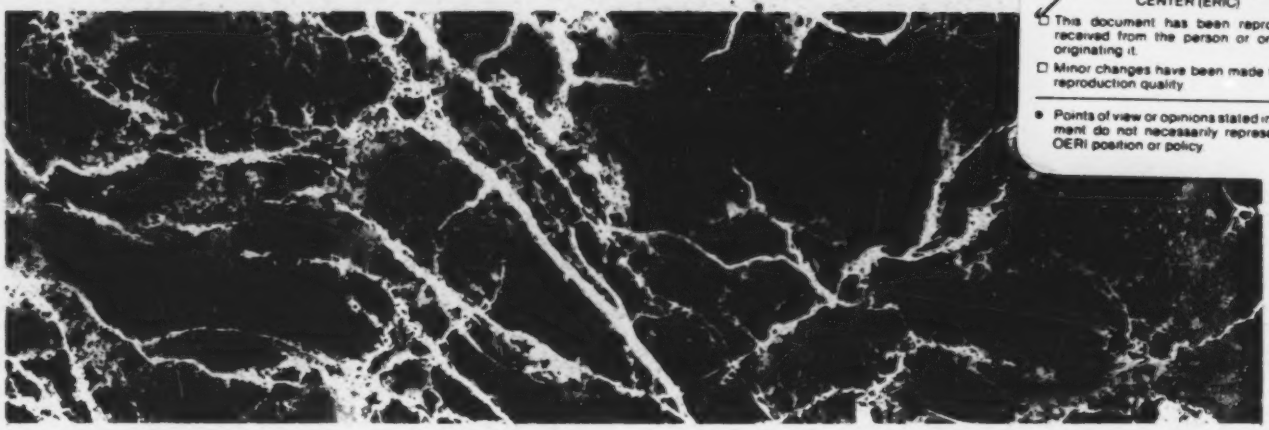

Iowa Statewide Follow-up Study

Adult Adjustment of Individuals with Severe/Profound Mental Disabilities One and Three Years After Leaving School

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Iowa Statewide Follow-up Study:

Adult Adjustment of Individuals with Severe/Profound Disabilities

One and Three Years after Leaving School

Patricia L. Sitlington
Iowa Department of Education
Des Moines, Iowa

Alan R. Frank
The University of Iowa
Iowa City, IA

Rori Carson
The University of Iowa
Iowa City, IA

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IOWA STATEWIDE FOLLOW-UP STUDY
TASK FORCE MEMBERS

John McClure, Supervisor
Keystone AEA 1

Irene Koster, Supervisor
Northern Trails AEA 2

Dixey Morrison
Special Education Director
Lakeland AEA 3

Dianne Bierma
WEC/Consultant
Area Education Agency 4

Beverly Fisher, Supervisor
Arrowhead AEA 5

Harold Eiten, WEC
Area Education Agency 6

John Struck, Supervisor
Area Education Agency 7

Jim Kay, Asst. Director
Mississippi Bend AEA 9

Paula Vincent, Asst. Director
Grant Wood AEA 10

Jim Kline, WEC/Consultant
Heartland AEA 11

Joe Lux, Asst. Director
Western Hills AEA 12

Cal Sinn, Supervisor
Loess Hills AEA 13

Brad Riley, WEC
Green Valley AEA 14

Bill Marks, Asst. Director
Southern Prairie AEA 15

Ed Longanecker, Supervisor
Great River AEA 16

Tom Jeschke
Special Education Director
Des Moines Public Schools

Dennis Thurman, Superintendent
Iowa Braille and Sight Saving
School

Preface

This monograph is one product of the Iowa Statewide Follow-up Study. Monographs have been developed, or are currently being completed, on the other major disability groups. An Action Group of the Iowa Statewide Follow-up Study Task Force also has been formed to draft specific programming recommendations based upon the data collected.

The follow-up study is a five-year project funded by the Iowa Department of Education, Bureau of Special Education, using EHA Part B discretionary funds. The purpose of this project is to determine the adult adjustment of special education graduates and dropouts (of all disabilities and program models) throughout the state of Iowa. The Iowa Statewide Follow-up Study is a joint effort of the Bureau of Special Education, Iowa Department of Education; the 15 Area Education Agencies in Iowa; Des Moines Public Schools; Iowa Braille and Sight Saving School; and the Division of Special Education, University of Iowa.

We gratefully acknowledge Merry Maitre, who originated the Iowa Statewide Follow-up Study; Dr. Timothy Z. Keith, who helped refine the data gathering procedures; Valerie Cool and Linda Cooper, who served as research associates for the project; and the Special Education Directors, Task Force members, and interviewers, who made the project a success. We also thank the individuals with disabilities who generously shared their stories and experiences with us.

For more information on the Iowa Statewide Follow-up Study, contact:

Dr. Patricia L. Sitlington, Project Director
Bureau of Special Education
Iowa Department of Education
Grimes State Office Building
Des Moines, IA 50319-0146
(515)281-3176

Abstract

The parents of 14 individuals with severe/profound mental disabilities were interviewed one and three years after their sons/daughters graduated from or "aged out" of high school. Two categories of information were sought concerning the adult adjustment of these individuals. General status variables included marital status, place of residence, agencies contacted about employment opportunities, financial resources, leisure activities, means of transportation, sources of help in resolving problems, and amount of postsecondary training. Employment variables included location of employment, wages, number of hours worked per week, and job benefits received. Results indicated that both one and three years after exiting high school all participants were very dependent upon others for housing, transportation, and financial assistance. Ten of the 14 individuals were employed three years after exiting high school, but all in sheltered workshops with an average wage of $0.09 per hour. There was little change in the life circumstances of the individuals between Years 1 and 3. The few changes that were found were mixed in terms of improved adult adjustment.

Iowa Statewide Follow-up Study:

Adult Adjustment of Individuals with Severe/Profound Mental Disabilities

One and Three Years After Leaving School

The adult adjustment of persons labelled mentally retarded has been the focus of a number of recent investigations (e.g., Frank, Sitlington, Cooper, & Cool, 1990; Hasazi, Gordon, Roe, Hull, Finck, & Salembier, 1985). This population also has been included in studies concerning the adult adjustment of individuals with mild handicaps (Clark, Hayden, & Lezzer, 1987; Edgar, 1987; Halpern & Benz, 1987; Hasazi, Gordon, & Roe, 1985; Mithaug, Horiuchi, & Fanning, 1985).

Only a few follow-up or follow-along studies have reported data concerning the adult adjustment of persons with moderate to severe mental retardation. Kregel, Wehman, Seyfarth, and Marshall (1986) studied the adult adjustment of 300 individuals with mental retardation, 117 of which were labelled moderately or severely mentally retarded. They reported that 92% of the subjects were living with parents or relatives, and an additional 5% resided in alternative living arrangements. Only 3% were living independently. Almost all the individuals demonstrated some degree of independence relative to independent living skills (e.g., self-care, mobility, and use of community facilities). Participation in social activities was most often passively oriented and conducted within the individuals' own homes. More than 20% cited lack of work skills, transportation, and lack of money as problems. In a related report involving the same individuals, Wehman, Kregel, and Seyfarth (1985) found an employment rate of only 21% among those individuals who were moderately or severely mentally retarded; 11 worked in sheltered workshops and 14 were in competitive employment. The majority were earning $100 or less per month and less than one fourth were receiving fringe benefits.

Thurlow, Bruininks, and Lange (1989) also conducted a follow-up study concerning individuals with moderate to severe mental retardation. Data were collected on persons who had been out of school for varying time intervals (1-2 years, 3-5 years, and 7-10 years). Almost two thirds were living with parents; another 37% in residential centers. None of the individuals was living independently. The employment rate was 42%, most often part time and in sheltered settings, for those out of school 1-2 years (the group most relevant to the present study). Eighty-nine percent were receiving SSI support.

Two recent studies were located which reported follow-up data separately for individuals labelled severely or profoundly mentally retarded. Haring and Lovett (1990) included a group of 9 individuals with severe/profound mental retardation in their investigation of the adult adjustment of 129 special education high school graduates. However, data were reported separately for the S/P group on only a few variables. Six of the subjects were described as being employed in day activity centers. One third were living in each of the following settings: group home, parent/relative, and institution; none of the individuals was living independently. Transportation used by these persons was provided by agencies, or friends and relatives; none used public transportation.

The National Longitudinal Transition Study of Special Education Students (Valdés, Williamson, & Wagner, 1990) contained a cohort of 47

individuals with severe mental retardation who either graduated (30%), dropped out (23%), were suspended/expelled (11%), or aged out of high school (37%). Use of the remaining descriptive data is limited, however, because they are presented by grouping 155 subjects whose ages ranged from 15 to over 21 years and were either still in high school or out of school from one to two years. Analysis of the "pooled" results show the following: (a) of 24 respondents, all were single; (b) 77% of 130 respondents lived with parents or relatives, 11% lived in a facility or institution, 8% lived in a group home, and none lived independently; and (c) 2% of 128 respondents were part-time employees in competitive jobs, none worked full time in competitive jobs, 3% were employed in sheltered workshops, 15% were in work study programs, and 78% were unemployed.

Although a fair amount of information is available concerning the adult adjustment of persons with mild to moderate mental retardation, very limited data have been reported concerning young adults with severe to profound mental retardation. The present study was a subcomponent of the Iowa Statewide Follow-up Study, which was a five-year project designed to study cohorts of randomly selected special education graduates and dropouts (of all disabilities and program models) throughout the state of Iowa. This subcomponent was designed to investigate the adult adjustment one and three years out of school of individuals with severe/profound mental disabilities who had been graduated from or "aged out" of programs operated by the public schools. Variables addressed in this study include: (a) general adult status (e.g., marital status, leisure activities), and (b) employment variables (e.g., percent employed, location of jobs, classification of jobs, wages).

Method

Participants

The sample for this investigation was the Class of 1985, surveyed one year and again three years after exiting high school. Each of the 15 Area Education Agencies (AEAs) in the state of Iowa prepared a list of special education students (all exceptionalities) who were graduated from, or "aged out" of, high school at the end of the target year. For each AEA, 50% of the students were randomly selected for inclusion in the sample. At Year 3 for each group, interviewers sought to survey the entire 50% random sample selected at Year 1.

School records of individuals were examined to obtain relevant information, including each student's primary disability label and program model at the time of exit from school. Seventeen (17) individuals in the sample were labelled severely/profoundly mentally disabled (S/P) while in high school. Of these 17, three were eliminated from the data analyses reported here (two had IQs above the range typically associated with persons labelled S/P, and only Year 3 interview data were available for one individual). Relevant high school data for the remaining 14 participants (82% of the individuals labelled S/P in the sample) are presented in Table 1. Sixty-four percent (9) of the interviews were conducted face-to-face with the participant's parents; 29% (4) were conducted with parents by telephone. The method of interview for one individual was not recorded. In several cases, formal IQ scores were not recorded in the students' files; it is not uncommon for IQ testing to be omitted from the assessment of persons with severe/profound disabilities.

The term program model in Table 1 is used synonymously with type of special education classroom attended by individuals while in high school. The

Table 1

High School Status of Individual Subjects
on Selected Variables

Subject No.	Selected Variables				
	Gender	Full Scale IQ	Program Model Attended	Type of HS Diploma	Type of Vocational Ed
1	Male	?	SSC	Certificate of Completion	None
2	Male	?	SSC	?	Specially-designed only
3	Female	22	SSC	Certificate of Completion	Specially-designed only
4	Male	30	SSC	Certificate of Completion	Specially-designed only
5	Female	34	SSC	Certificate of Completion	Specially-designed only
6	Female	35	SCI-L	Termination at Age 21	Specially-designed only
7	Male	24	SSC	Special Diploma	None
8	Female	?	SSC	Certificate of Completion	Specially-designed only
9	Male	?	SSC	Certificate of Completion	Specially-designed only
10	Male	?	SSC	Certificate of Completion	Specially-designed only
11	Male	?	SSC	Certificate of Completion	Specially-designed only
12	Male	?	SSC	Certificate of Completion	Specially-designed only
13	Female	30	SSC	Special Diploma	None
14	Male	20	SSC	Certificate of Completion	None

? = Information not recorded

student in a special class with little integration (SCIN-L) was integrated into regular classes for limited participation. Students in self-contained special classes (SSC) received all of their instruction from a special education teacher.

Instrumentation

The survey instrument used in this study was developed by project staff in conjunction with a task force of representatives of the 15 AEAs in the state of Iowa, the largest public school district in the state, and the state schools and correctional facilities. This task force identified the content areas to be covered in the interview form, based on previous follow-up studies conducted in other states and on other categories of information task force members felt would be useful in making programming decisions in their AEAs.

The survey instrument was designed to provide the following types of information: background information about students (e.g., test scores from high school, disability label, instructional program model); information pertaining to their high school programs (e.g., number of regular and special vocational education courses taken); information about current life circumstances (e.g., marital status, living arrangements, leisure activities); and information on current employment (e.g., location of current job, salary, hours worked per week).

Procedure

Interviews were conducted by professionals such as work experience coordinators, consultants, school psychologists, and teachers from each student's school district or AEA. These paid interviewers were trained and supervised by the Task Force member from their respective AEA. In addition, an in-depth interviewer handbook and sample interview forms were developed by project staff, and interviewers also participated in one or several one-hour training sessions on using these documents to insure consistency across interviewers. The project director was also on call to answer any general or specific questions arising from actual interviews.

All survey forms first were returned to the task force member for an initial content and completion check. Next, the forms were submitted to the Iowa Department of Education for a second content and completion check and for removal of any identifying information other than an identification number. All survey forms then were forwarded to The University of Iowa for a final content check, coding, computer entry and analysis. Data analyses were conducted using routines described in the *SPSS-X User's Guide* (1986).

Results

Table 2 presents information on the 14 individuals when they were out of school one and then three years. The Results section focuses on the general status of all of these individuals at both points in their adult life and on the status of those who were employed. For some variables, individuals were able to give more than one answer (e.g., agencies contacted about employment).

General Status

The marital status of all 14 participants was single both one and three years after exiting high school. One year out of school four individuals (28%) were living with relatives, seven (50%) were living in residential facilities or institutions, two (14%) were living in group homes and one (7%) was listed as buying a home. Three years out of school six (43%) individuals were living with relatives, five (36%) were living in residential facilities or institutions, and two (14%) resided in group homes. The place of residence of the remaining participant was categorized as "other." None of the participants was living indepen-

Table 2

Current Status of Individual Subjects at Years 1 and 3 on Selected Variables

Subject by Year	Post-High School Variables						
	Residence	Employment Status	Location of Job	Wages per Hour	Hours Worked per Week	Time in Current Job	No. Leisure Activities
Subject 1							
Year 1	Facility	Employed	Workshop	?	21-37	1-2 years	1-3
Year 3	Other	Employed	Workshop	$0.20	21-37	2+ years	0
Subject 2							
Year 1	Buy home	Employed	Workshop	?	37.5+	<1 year	0
Year 3	Relative	Employed	Workshop	?	21-37	2+ years	0
Subject 3							
Year 1	Group home	Employed	Workshop	?	21-37	1-2 years	1-3
Year 3	Group home	Employed	Workshop	$0.02	21-37	2+ years	4-6
Subject 4							
Year 1	Group home	Employed	Workshop	?	21-37	1-2 years	0
Year 3	Group home	Employed	Workshop	?	21-37	2+ years	1-3
Subject 5							
Year 1	Relative	Employed	Workshop	$0.37	21-37	<1 year	1-3
Year 3	Relative	Employed	Workshop	$0.01	<21	1-2 years	1-3
Subject 6							
Year 1	Relative	Employed	Workshop	?	21-37	1-2 years	1-3
Year 3	Relative	Employed	Workshop	$0.04	37.5+	2+ years	1-3
Subject 7							
Year 1	Facility	Employed	Workshop	$0.20	21-37	1-2 years	1-3
Year 3	Facility	Employed	Workshop	$0.20	21-37	2+ years	1-3
Subject 8							
Year 1	Relative	Employed	Workshop	$0.10	21-37	<1 year	1-3
Year 3	Relative	Employed	Workshop	$0.08	21-37	2+ years	1-3
Subject 9							
Year 1	Relative	Employed	Workshop	$0.05	21-37	<1 year	4-6
Year 3	Relative	Employed	Workshop	$0.04	37.5+	2+ years	4-6
Subject 10							
Year 1	Facility	Unemployed (Other)	NA	NA	NA	NA	1-3
Year 3	Facility	Employed	Workshop	$0.14	21-37	1-2 years	1-3
Subject 11							
Year 1	Facility	Unemployed (Disabled)	NA	NA	NA	NA	1-3
Year 3	Relative	Unemployed (Disabled)	NA	NA	NA	NA	0
Subject 12							
Year 1	Facility	Unemployed (Disabled)	NA	NA	NA	NA	0
Year 3	Facility	Unemployed (Disabled)	NA	NA	NA	NA	0
Subject 13							
Year 1	Facility	Unemployed (Disabled)	NA	NA	NA	NA	0
Year 3	Facility	Unemployed (Disabled)	NA	NA	NA	NA	1-3
Subject 14							
Year 1	Facility	Unemployed (Other)	NA	NA	NA	NA	0
Year 3	Facility	Unemployed (Other)	NA	NA	NA	NA	0

? = Information not recorded
NA = Not applicable

dently. During the period from one to three years out of school, two individuals had moved from a residential facility or institution, one to a relative's home and one to a living arrangement classified as "other." One additional individual had moved from buying a home to living with relatives.

Nine (64%) individuals were employed one year out of school. They were still employed three years after leaving school and were joined by one additional individual (n = 10; 71%). Three subjects listed the reason for unemployment as "disabled and receiving supplemental security income." Two individuals listed the reason for unemployment as "other" the first year out; one of these individuals was employed three years out of school. All current jobs were located in a sheltered workshop or work activity center. Additional information concerning employed persons is reported below.

When respondents were asked three years out of school about agencies which they had contacted concerning possible employment opportunities, the majority (n = 10; 71%) said they had talked to workshops, and 6 (43%) said they had contacted the Iowa Department of Human Services. This number was up from Year 1 when eight (57%) individuals said they had talked to a workshop and four (25%) had contacted the Department of Human Services. None of the respondents indicated talking to Vocational Rehabilitation, Job Service of Iowa, or Job Training Partnership Act agencies either one or three years after leaving school.

The financial status of participants was explored during the interview three years after exiting high school. Seven individuals (50%) were paying a portion of their living expenses, while the remaining seven persons contributed no money toward their living expenses. In the three years out of school one individual shifted from paying none to some living expenses. All individuals were receiving supplemental security income (SSI). One year out of school eight (57%) individuals received financial assistance from parents and five (36%) from the Department of Human Services. Three years out of school, six (43%) individuals received assistance from parents and six obtained help from the Department of Human Services.

Information also was sought concerning modes of transportation used by participants to get around the community. Special transportation services for persons with disabilities and dependence upon friends or relatives were the primary modes of transportation. One year out of school nine (64%) individuals used special transportation and ten (71%) depended on others. Three years out of school ten individuals used special transportation and one less individual depended on others. One person walked to some destinations. None of the participants used city buses as a means of transportation.

Three years after exiting high school seven (50%) individuals were involved in 1-3 leisure activities, and another two (14%) were participating in more than three recreational activities. Five (36%) individuals were not involved in any leisure activities. Two individuals reported a decrease in the number of leisure activities from Years 1 to 3, and three individuals reported an increase in such activities. The most frequently reported (n = 7; 50%) leisure activity was athletic in nature, followed by dining out (n = 3; 21%). Two (14%) individuals spent time in each of the activities categorized as outdoor activities, reading, and attending movies. Four (29%) individuals belonged to a church or social club. Type of leisure activity remained similar at both the one and three year survey periods.

Respondents were asked to identify sources of help used by participants when they were experiencing problems.

At the three year interview, the most commonly named resources were parents (n = 6; 43%), followed by mental health professionals (n = 3; 21%). No other sources of help were mentioned. Results were similar when individuals were surveyed one year out, although one individual mentioned a sibling and one less individual named mental health professionals.

About one fourth (n = 4; 29%) of the individuals had participated in some type of training after leaving high school. Two persons were involved in Adult Basic Education programs and two received training in private programs. The number of participants in postsecondary training was up by one person from the Year 1 interview.

Characteristics of Employed Persons

Of the 10 individuals who were employed three years out of school, almost all (n = 8; 80%) had been working at the same job for more than 2 years; the remaining persons (n = 2; 20%) had worked from 1-2 years in their current job. As reported previously, all employed persons had jobs in a sheltered workshop or activity center. The average wage earned per hour at Year 3 among employed persons (n = 8) was $0.09, and ranged from $0.01-$0.20 per hour. This average wage was down from $0.18 per hour at Year 1 (n = 4; ranging from $0.05-$0.37 per hour). Wages for three of the four workers for whom wages were reported actually decreased from Years 1 to 3. For the remaining worker, wages were unchanged from Years 1 to 3.

Three years out of school, the majority (n = 7; 70%) of employed individuals worked between 21-37 hours per week, a drop from Year 1 when 8 (89%) were working 21-37 hours per week. Two (20%) individuals were employed full time, and 1 (10%) person worked less than 21 hours per week. Of the nine individuals employed one year out of school, two increased the number of hours worked (from 21-37 to 37.5+ hours per week) and two decreased the number of hours worked by the third year out of school.

Respondents were asked about job benefits received by employed participants. No one was receiving health insurance. Four (40%) were given vacation time, and only three (30%) received sick leave. Benefits did not change from the one to three year survey period.

Discussion

When the data relative to current employment from the present investigation are compared to other studies which have focused on persons with moderate/severe/profound mental disabilities, the results appear to present a "good news, bad news" picture. The results of this study are similar to those reported by Haring and Lovett (1990) which indicate higher rates of employment than reported in other studies (Wehman, Kregel, & Seyfarth, 1985; Thurlow, Bruininks & Lange, 1989; Valdés, Williamson, & Wagner, 1990). However, the latter studies did find some individuals working in competitive employment, which was not the case in either the present or Haring and Lovett study. The results of the present study paralleled those of the Haring and Lovett; Thurlow, Bruininks, and Lange; and Valdés, Williamson, and Wagner studies relative to place of residence. All persons labelled S/P were residing with relatives or in other supervised settings (i.e., group homes or residential centers) and none was living independently. Kregel, Wehman, Seyfarth, and Marshall (1986) found most living with relatives or in residential centers, but three individuals were living independently.

The results of this investigation indicate that there was little change between Years 1 and 3 in the life circumstances of the 14 participants; the few changes that were found were mixed in

terms of improving the adult adjustment of the individuals involved. None of the individuals worked in either competitive jobs or in community-based jobs supervised by rehabilitation professionals; rather, all persons worked in sheltered workshops or work activity centers even after being out of school three years. Hourly wages were extremely low for all individuals for whom such data were available. In only two instances did individuals move from part- to full-time work; most remained part-time workers. In two other cases, individuals actually decreased in number of hours worked the longer they were out of school. In short, although all workers had been employed in their current job from 1-2 years (and 80% were over 2 years), little upward mobility was experienced and no one moved to a community-based job.

Perhaps these judgments concerning adult adjustment have relied too much on employment variables. However, when other data are considered, the results still are not encouraging. None of the individuals was living independently or semi-independently at Year 3. Five individuals had no leisure activities whatsoever at Year 3; of which three were unemployed (see Table 2). In addition, at Year 3 all individuals were dependent upon relatives, friends, or special services for financial assistance and transportation.

Are these results the best we can hope for when we consider the nature of these persons' disability? We think not. Hill, Wehman, Kregel, Banks, and Metzler (1987) reported the results of a longitudinal investigation of people with moderate and severe disabilities who participated in supported competitive employment. Although the results of this study relative to participants with severe disabilities ($\underline{n} = 3$) did not show savings to taxpayers, the project demonstrated steady improvement over time relative to participants with moderate disabilities to the point where substantial tax payer savings were realized, to say nothing of the increased community participation of the individuals involved. These improvements involved savings in SSI payments, savings as the result of reduced alternative program costs (e.g., sheltered workshops, day programs), and estimated total taxes paid by the persons with moderate and severe disabilities. Steele, Strang, Burrows, Kiburz, Vincent, and Sitlington (1990) reported the results of an interagency transition project in Iowa involving students from classrooms for students labelled moderately and severely/profoundly mentally disabled. Through early transition planning and close cooperation between the school and adult service providers, 11 of 13 program graduates were placed in community-based employment the first year of the project, followed by 9 of 16 graduates the second project year. In the two years preceding the project, 0 of 7 graduates and 1 of 7 graduates, respectively, were placed in community-based employment..

Research reports in the literature also support the notion that persons with severe/profound disabilities can learn other skills associated with a more satisfying adult adjustment. Nietupski et al. (1986) demonstrated that persons labelled S/P could be taught self-initiated and sustained leisure participation, and that these skills maintained from one week to four months following program completion. Persons labelled S/P are capable of learning some grocery shopping (Nietupski, Welch, & Wacker, 1983) and cooking skills (Robinson-Wilson, 1977). Further, persons labelled S/P can be taught to ride a public bus system (Certo, Schwartz, and Brown, (1977).

What is needed to move from the results of this study to what we know is possible for individuals labelled S/P? What is needed to move from sheltered employment at almost non-existent wages and from dependence upon relatives and special services to employment and daily life in the community? We propose three major thrusts of activity. First, the focus

of the curriculum from the time students enter school must be on functioning in the community. As students approach junior and senior high school age the majority of their instruction should be in community-based settings and focused on being as independent as possible in these settings. This includes specific instruction in skills needed for independent living, interpersonal relationships, leisure activities, and employment.

Second, we must work to develop support systems within the community that will enable the individual to function as an adult in community-based settings. This includes a continuum of residential services, as well as support systems and programs that make it possible for individuals with disabilities to participate in leisure activities with individuals who are not disabled. In terms of interpersonal relationships, it means providing opportunities and assistance for individuals with severe disabilities to develop relationships with others--both those with and without disabilities. In terms of employment, it means a commitment to community-based employment and implementing a system of supported employment (e.g., Rusch, 1990) which provides ongoing support services for individuals in integrated work settings in the community for real wages. Along with developing the needed support system, we also must train staff hired by adult service providers so that they have the skills needed to work with individuals with severe disabilities.

Third, and possibly most important, we need to build a bridge between what happens in the school and what happens in adult life through systematic transition planning which is included in the Individualized Education Plan. It is our feeling that this planning should begin at least by age 14 and should involve the school, parents, and adult service providers as early as possible. Transition planning has recently been mandated by the Individuals with Disabilities Act. Such a transition planning process allows school and adult agency personnel to work closely with students and their parents to meet the common goal of life and employment in the community.This transition planning process must extend into the individual's postschool life and culminate in a "handoff" of responsibility from the school to the appropriate adult service provider(s). This may mean the continuation of the multidisciplinary transition planning team past the student's departure from school. Just as we ask adult service providers to enter the transition planning process while students are still in school, we may need to ask school personnel to continue as members of the planning team as students enter adult life.

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